

Early Support for Infants & Toddlers



Kids' Potential, Our Purpose

Practice Guide: Infants and Toddlers with Sensory Disabilities (Deaf/Hard of Hearing, Blind/Visually Impaired, or Deaf-Blind)

Background

With the advent of universal newborn hearing screening, with 96% of all newborns screened, numbers of infants in Washington State identified with hearing loss have skyrocketed. Early Support for Infants & Toddlers (ESIT), in collaboration with the Washington State Center for Childhood Deafness and Hearing Loss (CDHL), the Department of Health (Screening and Genetics) Early Hearing-loss Detection, Diagnosis, and Intervention program (EHDDI), the Office of Deaf & Hard of Hearing Services (ODHH), and Washington Sensory Disabilities Services (WSDS), has worked to develop new systems and services to support families of birth-to-three year olds who are identified as **deaf or hard of hearing**, regardless of where they might live in the state. Our charge is to ensure that Washington meets the national EHDDI goal: *infants are enrolled in early intervention services by six months of age when a hearing loss is found.*

Concurrently, ESIT collaborated with representatives of Washington State School for the Blind (WSSB), Department of Services for the Blind (DSB), the Office of Superintendent of Public Instruction (OSPI), WSDS, and Washington Talking Book and Braille Library (WTBBL) to develop new systems and services to support families of birth-to-three year olds who are identified as **blind or visually impaired (BVI)**. *The goal is to ensure that infants who are BVI are identified and enrolled in early intervention services within four months following diagnosis of a visual condition that may be associated with visual impairment.* In particular, this work group aims to improve access to appropriate specialty services, i.e., early supports provided and guided by Teachers of the Visually Impaired (TVIs) and Certified Orientation and Mobility Specialists (COMS), who function as integral partners on the early intervention team.

Via representation of the WSDS Deaf-Blind Project in the above work, we also have addressed the needs of infants and toddlers with **combined hearing loss and visual impairment (DB)**, who present special challenges in our early identification efforts. *The goal is to ensure that infants and toddlers with dual sensory loss are identified during the early intervention years, prior to transition to preschool.*

As of 2016, this work has resulted in new processes for data sharing among agencies to increase speed of referrals to early intervention, collecting demographic data on infants and toddlers with sensory disabilities, and increasing services available to local communities to better

support these families. In particular, this group has focused on increasing supports to rural and remote communities that often have less access to the specialized services these young children need in order to develop at a rate commensurate with their peers.

Eligibility Criteria for Early Intervention Services

Before introducing the parts of this Practice Guide, a review of eligibility criteria for infants and toddlers highlights an important fact: **any child with a diagnosed visual impairment and/or hearing loss as described below is eligible for early intervention services in Washington State.** See the *ESIT Developing WAC: Washington Administrative Code* (January 2014 draft), WAC 179-300-01010 (pp. 9-11). Eligibility criteria are presented in Figure 1 as written in the 2014 WAC.

Figure 1.

Eligibility Criteria for Sensory Disabilities

(2) In the case of hearing and vision, the criteria listed within hearing impairment and vision impairment in subsections (i) and (j) of this section apply.

<u>Eligibility Criteria for Visual Impairment</u>	<u>Eligibility Criteria for Deafness/Hearing Loss</u>
<i>Visual Impairment-infants and toddlers with visual impairment/blindness are:</i>	<i>Deafness/hearing loss that adversely affects a child's development is:</i>
<ul style="list-style-type: none"> i) Those children who have a visual impairment that adversely affects the child's development, even with correction. Eligibility shall be dependent on the documentation of a visual impairment, including one or more of the following conditions: ii) Legal blindness or visual handicap, as they are customarily defined, either in terms of qualifying reduction in visual acuity and/or a qualified reduction in visual fields. iii) A visual impairment that is progressive in nature and can be expected to lead to blindness within a reasonable period of time. iv) If a visual acuity or field cannot be determined: <ul style="list-style-type: none"> A) The qualified personnel must identify a diagnosis or medical history that indicates a high probability of visual loss that may adversely affect the child's development B) A functional vision evaluation by a qualified professional is necessary to determine eligibility. 	<ul style="list-style-type: none"> (i) Unilateral sensorineural hearing loss and/or permanent conductive hearing loss of forty-five dB or greater. (ii) Bilateral sensorineural hearing loss and/or permanent conductive hearing loss that includes: <ul style="list-style-type: none"> (A) Hearing loss of twenty dB or greater, better ear average of the frequencies five hundred, one thousand, and two thousand Hz; (B) High frequency loss greater than twenty-five dB at two or more consecutive frequencies or average of three frequencies between two thousand and six thousand Hz, in the better ear; (C) Low frequency hearing loss greater than twenty-five dB at two hundred and fifty and five hundred Hz, in the better ear; (D) Thresholds greater than twenty-five dB on auditory brainstem response threshold testing in the better ear; or (iii) A six-month history of fluctuating conductive hearing loss or chronic middle ear effusion/infection of three months, unresolved past initial evaluation; or [sic]

Eligibility Criteria for Deaf-Blindness

Infants and toddlers who meet the above eligibility criteria for both hearing loss and visual impairment will also qualify for supports from the WSDS Deaf-Blind Project. *It is important to note, however, that children who are eligible under the following criteria also are at high risk for dual sensory loss. Special attention should be paid to ensure that both hearing and vision have been appropriately screened.*

- (4) A child is eligible if he or she has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. Such conditions include, but are not limited to:
- (a) Chromosomal abnormalities;
 - (b) Genetic or congenital disorders;
 - (c) Sensory Impairments [sic];
 - (d) Inborn errors of metabolism;
 - (e) Disorders reflecting disturbance of the development of the nervous system;
 - (f) Congenital infections. . .
 - (h) Disorders secondary to exposure to toxic substances, including fetal alcohol syndrome.
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A child who meets one or more of the eligibility criteria above for hearing loss and/or visual impairment needs no additional evaluation to determine eligibility for early intervention services. The sensory loss alone creates the eligibility. Refer to the ESIT publication titled ***Practice Guide: Evaluation, Assessment, Eligibility and the Initial IFSP*** (October 2013). Children with sensory disabilities would be considered eligible under Path 1: Medical Diagnosis.

This Practice Guide will introduce the following:

1. Pathway to Services Flowcharts (for BVI and DHH) (Appendix 1)
2. Registry Form for B-3 BVI and DHH (Appendix 2)
(and) American Printing House (APH) Federal Quota (BVI) (Appendix 2.b)
3. Self-Evaluation Tool for Early Intervention Programs on Services to Birth-to-Three Year Olds with Sensory Disabilities (Appendix 3)
4. Areas to Address with All Families Whose Infants/Toddlers are Identified as Blind or Visually Impaired, Deaf or Hard of Hearing, or Deaf-Blind (Appendix 4)

Following are brief descriptions of each section of this Practice Guide.

1. Pathway to Services Flowcharts (for BVI and DHH)

Because of (a) differences in how vision and hearing concerns are identified in the first months of life, and (b) federal legislation mandating newborn hearing screening, the pathway to early intervention services is different for infants with blindness/visual impairment and those who are deaf/hard of hearing.

A. Infants who are Deaf/Hard of Hearing

The Department of Health EHDDI program created a surveillance tracking and monitoring system and trained hospital birthing center staff and midwives to conduct universal newborn hearing screening. Refer to **Appendix 1.a. Pathway to Services: DHH**, which depicts steps between newborn hearing screening and entry into early intervention, as you follow the description below.

When a child is diagnosed with a hearing loss, the audiologist refers the family directly to the Local Lead Agency (LLA) via an EHDDI data-sharing link with the ESIT database. The Family Resources Coordinator (FRC) obtains parental permission to complete a **Registry Form** (see p. 5). If needed, a conversation between the CDHL birth-to-preschool Outreach Director and the FRC determines local/regional supports for the family, and also ensures that a certified or licensed professional in early childhood deaf education assists in developing the family's Individualized Family Services Plan (IFSP).

B. Infants who are Blind/Visually Impaired

Refer to **Appendix 1.b. Pathway to Services: BVI**, which depicts steps between birth and entry into early intervention, as you follow the description below.

When a child is diagnosed with a visual impairment and the family referred to its Local Lead Agency, the FRC obtains parental permission to complete a **Registry Form** (see p. 5). If needed, a conversation between WSSB's State Birth-to-Three Coordinator and the FRC can determine local resources for supports for the family, and also ensures that a person with expertise in early childhood visual impairment assists in developing the family's Individualized Family Services Plan (IFSP).

C. Infants who are Deaf-blind (Combined Vision and Hearing Loss)

Infants and toddlers with diagnosed visual impairment *and* hearing loss, or with a medical diagnosis that puts them at risk for both (e.g., prematurity, cerebral palsy, CHARGE syndrome), are eligible for consultative services from the WSDS Deaf-Blind Project. WSDS staff will help determine next steps for in-person and distance services. These are usually delivered in coordination with the Early Intervention team. Calls/emails are welcomed from both service providers and family members.

The FRC (or other IFSP team member) ensures that a Registry Form (p. 5) is completed and submitted for each child diagnosed with a hearing loss, visual impairment, or combined hearing loss and visual impairment (deaf-blindness).

Why are different "Pathways to Services" necessary for these children and families?

Because optimal outcomes are best achieved with appropriate specialized services for families, families must have access to staff with training and experience in supporting infants/toddlers who are DHH, BVI, or DB. If the LLA and/or early intervention (EI) agency has a well-developed plan for providing such supports to these unique populations, the team proceeds with developing the IFSP. (See **Self-Evaluation Tools for Early Intervention Agencies** on p. 6.)

DHH. If the LLA/EI agency does not have a certified professional in deaf education within the community to support families of young children with hearing loss, then the FRC, in cooperation with CDHL, will identify potential early intervention partners both within and outside of the local community. In addition to local birth-to-three programs, these partners might include individuals working in a specialty program for infants/toddlers who are DHH, a nearby regional service center for the deaf and hard of hearing, or a Guide By Your Side™ (a parent-to-parent networking program).

BVI. If the LLA/EI agency does not have a certified teacher of the visually impaired (TVI) within the community to support families of young children with blindness/visual impairment, then the FRC, in cooperation with WSSB, will identify potential early intervention partners. These partners might include Department of Services for the Blind's Child and Family Program.

Consultative specialty services for DHH, BVI, and DB populations may be delivered via “tele-therapy” or “tele-intervention” through the use of technology, in addition to in-person services.

As with any IFSP, services will be driven by the family's identified priorities and needs. To help guide families and FRCs in focusing on critical content areas, however, FRCs can refer to **Areas to Address with All Families** (see p. 6). This document identifies several areas as the most essential for families of infants and toddlers with sensory disabilities to address, with support from partners with expertise in early childhood deafness, visual impairment, and deaf-blindness.

2. Registry Form for B-3 Children with Sensory Disabilities (<http://www.wssb.wa.gov/B3>)

WSSB and CDHL are state agencies required by law (RCW 72:40.070) to collect data on the population of children with sensory disabilities in the State of Washington. This information is confidential and is used to justify funding requests and to develop appropriate programs to support children who are deaf/hard of hearing, blind/visually impaired, and deaf-blind.

The Registry Form is the document used to register all children between the ages of birth and three years who have been diagnosed with a sensory disability:

- (a) deaf or hard of hearing—including children with any type or degree of hearing loss; or
- (b) blindness or visual impairment—including children with any type or degree of visual impairment, including cortical visual impairment (CVI); or
- c) deaf-blindness. If the child is suspected or known to have *both* hearing loss and visual impairment, the “Registry Type” drop-down menu allows that to be selected as well.

The Registry Form is online and has four parts: 1) Identifying Information, 2) Audiological Information, 3) Vision Information, and 4) Early Intervention Services.

Once completed, the Registry Form is submitted electronically to a secure database. This process gathers demographic data on children across the state, is aggregated to protect confidentiality, and documents needs to funding agencies and others. *It is not a referral to a particular program, nor a request for technical assistance or consultation, and families will not be contacted without a formal request for technical assistance or consultation by the FRC.*

The online Registry Form is available on the WSSB website: <http://www.wssb.wa.gov/b3>

2.b American Printing House (APH) Federal Quota (BVI)

The APH is the official supplier of educational materials to all students in the U.S. who meet, or function at, the definition of blindness or visual impairment. *This includes children under the age of 3.* In Washington, WSSB's Ogden Resource Center (ORC) is the state-appointed Instructional Resource Center (IRC) designated to distribute materials to children and families.

Early Intervention agencies register as an account holder (one time) with the ORC and then register individual infants/toddlers who qualify (yearly). The agency can then order and receive products and materials created especially for children with visual impairments to use in the home or other natural environments such as child care centers.

Materials include books with braille and textured pictures, games and toys, materials specific for children with CVI, and resources for both service providers and families. Materials are free to the agency and families, as they are provided by the federal quota funds. Most of the items are considered "consumable" and do not need to be returned. The TVI on the family's IFSP team will assist the agency in the registration process and the determination of appropriate materials, as well as instruction in their use within the routine of the child and family.

For instructions for completing APH registration, see Appendix 2.b.

3. Self-Evaluation Tool for Early Intervention Programs on Services to Birth-to-Three Year Olds who are Blind or Visually Impaired or Deaf or Hard of Hearing

The purpose of this tool is to help LLAs and EI agencies evaluate their readiness to support families with newly identified birth-to-three year olds with sensory disabilities. Some programs and counties have well-developed services to support families; others have few specialized resources and little previous experience in serving families of young children who have hearing loss and/or visual impairment. Partnering with CDHL, WSSB, and WSDS/Deaf-Blind Project will help LLAs determine strengths and needs, and can ensure that appropriate services are located or developed. LLAs that complete this self-evaluation will be better prepared to collaborate with CDHL, WSSB, and the WSDS/Deaf-Blind Project.

See Appendix 3 of this Practice Guide for the self-evaluation tool.

4. Areas to Address with All Families Whose Infants/Toddlers are Identified with Sensory Disabilities: BVI, DHH, and DB

This document is intended to guide the FRC through "first steps" following referral of a child with sensory disability to the LLA, including developing the first IFSP, and contains three sections: Medical Records, Referrals to Resources, and Areas of Understanding for All Families.

See Appendix 4 of this Practice Guide.

Key references and state and national resources on sensory disabilities may be found below. This is not intended to be a comprehensive list.

References

- Hatton, D., Anthony, T., Bishop, V., Gleason, D., Greeley, J.C., Miller, T., Moore, S., Riggio, M., Robinson, L., Teplin, S., & Tompkins, C. (2003). *Family-centered practices for infants and young children with visual impairments*. Position paper of the Division on Visual Impairments, Council for Exceptional Children. Arlington, VA: Council for Exceptional Children.
- Joint Committee on Infant Hearing (2013). Supplement to the JCIH 2007 position statement: *Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing*. *Pediatrics*, 131, e1324-e1349.
- Moeller, M.P., Carr, G., Seaver, L., Stredler-Brown, A. & Holzinger, D. (2013). Best practices in family-centered early intervention for children who are deaf or hard of hearing: An international consensus statement. *Journal of Deaf Studies and Deaf Education* (18:4), 429-445.
- Spungin, S.J., & Ferrell, K.A. (2007). *The role and function of the teacher of students with visual impairments*. Position paper of the Division on Visual Impairments, Council for Exceptional Children. Arlington, VA: Council for Exceptional Children.

Sample Resources for Infants and Toddlers with Sensory Disabilities

Washington State Resources:

- Department of Services for the Blind
<http://www.dsb.wa.gov/services/childrenandfamilies.shtml>
- Early Hearing-loss Detection, Diagnosis and Intervention (EHDDI)
<http://www.doh.wa.gov/earlyhearingloss>

Link to Parent Notebook:
http://www.doh.wa.gov/Portals/1/Documents/Pubs/344-017_EHDDIResourceGuideEng.pdf

Link to Resources by County Guide:
http://here.doh.wa.gov/materials/EHDDI-resources/13_EHDDIres_E15L.pdf
- Guide By Your Side (GBYS)
<http://www.wahandsandvoices.org/gbys/>
- Washington Sensory Disabilities Services (WSDS) - Infant/Toddler and Deaf-Blind pages
<http://www.wsdsonline.org/infant-toddler/>
<http://www.wsdsonline.org/video-library/blind-visually-impaired-videos/>
<http://www.wsdsonline.org/deaf-blind/>

- Washington State Center for Childhood Deafness & Hearing Loss (CDHL)
<http://www.wsdsonline.org/deaf-hard-of-hearing/>
- Washington State Hands & Voices
<http://www.wahandsandvoices.org/>
- Washington State School for the Blind (WSSB) – Birth to Three
<http://www.wssb.wa.gov/Content/oncampus/b3.asp>

National Resources (find more on the above Washington State websites):

- Centers for Disease Control and Prevention: Hearing Loss in Children
<http://www.cdc.gov/ncbddd/hearingloss/index.html>
- Family Connect
<http://www.familyconnect.org/parentsitehome.aspx>
- My Baby's Hearing
www.babyhearing.org
- National Center for Hearing Assessment and Management
www.infanthearing.org
- National Center on Deaf-Blindness
www.nationaldb.org
<https://nationaldb.org/library/list/35> (early intervention resources in library)
- Perkins School for the Blind
www.perkins.org
www.perkinselearning.org
- Wonder Baby
www.wonderbaby.org